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# Consulting a traditional healer and negative illness perceptions are associated with non-adherence to treatment in Indonesian women with breast cancer

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## Abstract

**Objective:** The aim of the present study was to test the association between psychosocial factors and delay in uptake of treatment and treatment non-adherence in Indonesian women with breast cancer.

**Methods:** Seventy consecutive patients with breast cancer who were treated at the Hasan Sadikin Hospital in Indonesia were recruited. They completed a demographic form, the non-adherence questionnaire, the Breast Cancer Knowledge Test, the Brief Illness Perception Questionnaire, the Multidimensional Health Locus of Control Scales, the Satisfaction with Cancer Information Profile and the Distress Thermometer.

**Results:** Seventeen (24%) out of 70 patients reported that they had delayed initiating treatment at the hospital, and nine (13%) out of 70 patients had missed two or more consecutive treatment sessions. In the bivariate analyses, we found no significant differences on any of the psychological variables between patients who delayed initiating treatment and those patients who did not, whereas patients who had missed two or more consecutive sessions had lower satisfaction with the type and timing of information provided and more negative illness perceptions than patients who had not missed their sessions. In multivariate regression analyses, consulting a traditional healer before diagnosis was associated with treatment delay ( $\beta = 1.27$ ,  $p = 0.04$ ). More negative illness perceptions ( $\beta = 0.10$ ,  $p = 0.02$ ) and whether a traditional healer had been consulted after diagnosis ( $\beta = 1.67$ ,  $p = 0.03$ ) were associated with missing treatment sessions.

**Conclusions:** Indonesian health professionals need to be aware of patients' negative illness perceptions and their unrealistic belief in traditional healers.

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## Introduction

Breast cancer is the most frequently diagnosed cancer among women both in developed and developing countries [1]. In Indonesia, breast cancer has emerged as the most frequent cancer and the leading cause of death, with an incidence rate of 36.2 and a mortality rate of 18.6 per 100,000 people [2,3]. A review study of cancer epidemiology in South-East Asian countries found that late presentation at the hospital for treatment was the major problem related to lower survival rates among women with breast cancer in Indonesia [4]. In addition, poor adherence to treatment is considered to be an important factor contributing to higher mortality rates in developing countries [5].

Non-adherence to treatment may appear in several forms: (a) not attending or coming late to appointments, (b) delay or not initiating a recommended treatment, (c) not completing behavioral recommendations, (d) not taking medication as prescribed, and (e) terminating the treatment prematurely [6]. A meta-analysis study about patient adherence that

involved 569 published studies found an average non-adherence rate of 25% and a non-adherence rate of 21% for cancer patients [7]. Specifically among breast cancer population, previous studies found about 16–32% of patients delayed initiating treatment [8,9], and approximately 30% of patients discontinued therapy early [10]. Our retrospective qualitative study in 50 breast cancer patients in Indonesia found that 42% had delayed the uptake of treatment at the hospital and 20% had missed two or more consecutive sessions during their treatment [11]. In a study among Indonesian childhood leukemia patients, approximately 25% of patients refused or abandoned therapy [12]. A study in Indonesian retinoblastoma patients found that 31.5% of patients temporarily refused medical treatment, whereas 18.2% of patients refused treatment permanently [13].

In general, psychosocial factors of non-adherence to treatment can be differentiated into three groups: cognitive, social, and emotional variables. Cognitive variables include patients' knowledge, risk perception, beliefs, and attitude to

breast cancer treatment, whereas social variables include social networks and social support [14]. Previous studies among breast cancer patients found that greater knowledge of the disease and treatment is associated with better adherence [15–17]. A review study of patients' illness perceptions and medication adherence found that negative illness perceptions were directly or indirectly associated with poor adherence to medication [18]. Patients' beliefs about disease (e.g., having cancer is a fate) and treatment (e.g., use of alternative medicine) were related to delay in seeking help for oral, breast, and cervix symptoms [19,20]. A review study about adherence to therapy with oral anti-neoplastic agents suggested that people with a strong belief that their behavior played a large role in determining their circumstances (internal locus of control) are more likely to adhere to a prescribed treatment regimen [21]. With regard to social variables, a meta-analysis study about social support and patient adherence to medical treatment found that better social support was associated with better adherence [22]. Another meta-analysis found that high levels of psychological distress were associated with poor adherence [23].

In our previous qualitative study, consecutive samples of 50 breast cancer patients were interviewed. We identified several psychosocial factors related to delay in seeking help and non-adherence to treatment, including, lack of awareness and knowledge, cancer beliefs, treatment beliefs, emotional burden, and unmet information needs [11]. The aim of the present study was to test the association between these psychosocial factors (i.e., knowledge, illness perception, health locus of control, satisfaction with information, and distress) and delay in uptake of treatment and treatment non-adherence in Indonesian breast cancer patients.

## Methods

### Participants

This study was part of a larger investigation in which the psychosocial aspects of 120 Indonesian breast cancer patients who were undergoing medical treatment (i.e., surgery, chemotherapy, and radiotherapy) at the outpatient surgical oncology clinic at Hasan Sadikin Hospital (HSH) in Bandung urban area were explored in two phases. The first group of 50 consecutive patients was recruited between April and June 2010, and the second group of 70 consecutive patients was recruited between June and October 2011 (the current study). The study included patients who were aged 18 years or older, had received a first diagnosis of breast cancer, had no psychiatric treatment history, and had an adequate command of the Indonesian language.

### Procedures

This study was approved by the Indonesian medical ethical committee and the Board of Directors of HSH.

First, we translated the relevant questionnaires, namely, the Breast Cancer Knowledge Test (BCKT), the Brief Illness Perception Questionnaire (BIPQ), the Multidimensional Health Locus of Control Scales (MHLC), the Satisfaction with Cancer Information Profile (SCIP), and the Distress Thermometer (DT), using the forward and back translation method. One of the authors of this study (A. I.), who is a clinical psychologist, translated the questionnaires from English into the Indonesian language; the back translation into English was carried out by an English language teacher (J. H.) who is a Native American and speaks the Indonesian language fluently. Upon completing the translation, a linguist (A. C.) examined the original English version and the back translation version of the questionnaires to assess the significance of any discrepancies. After some discussions with A. C., we finalized the Indonesian version of the questionnaires. A panel of experts (i.e., three Indonesian psychologists) assessed the content validity of the version. They reviewed the items of each questionnaire and commented on whether the items covered a representative sample of the behavior domain.

Second, eligible patients were approached by a member of the administration staff from the surgical oncology clinic. They asked patients for initial consent and referred patients who were willing to participate in the study to the research assistants. One of the research assistants followed up and arranged an appointment with the patients on their next visit. All data collections were conducted by 10 master's students in clinical psychology who were trained as research assistants and were supervised by A. I. (first author) and S. S. (fifth author). After signing the informed consent, patients were asked to complete a socio-demographic form, the non-adherence questionnaire, the BCKT, the BIPQ, the MHLC, the SCIP, and the DT. For those who were unable to complete the questionnaires unassisted (i.e., seven patients were illiterate), the research assistants read the questionnaires aloud and recorded the patients' answers on the questionnaires. Patients filled in the questionnaires in the waiting room of the clinic before their consultation with the physicians.

### Measures

#### Socio-demographic characteristics

A standard socio-demographic form was used to collect self-report data on age, marital status, education, employment status, family income, insurance status, travel time to hospital, time since diagnosis, family history of cancer, and use of traditional healer. The patients' medical records were also reviewed to obtain data on type and stage of cancer and type of treatment.

#### Adherence to treatment

Patients' adherence to treatment was assessed using a self report. We evaluated two forms of non-adherence: (1)

treatment delay and (2) not attending treatment appointments. As there is a strong association between delaying breast cancer treatment by 3 months or more and lower survival [24], we adopted a 3-month interval as our gold standard for treatment delay. A patient was categorized as a non-adherer according to the first definition if the period between the first diagnosis and the first admission at HSH was >3 months. A patient was categorized as a non-adherer according to the second definition if they were absent from two or more consecutive treatment sessions at HSH [25].

### Breast cancer knowledge

Patient knowledge was assessed using the BCKT [26]. This instrument comprises two sections: the first section consists of 12 items to assess individual breast cancer general knowledge, and the second section consists of eight items to assess individual knowledge about the curability of breast cancer. For each item, patients were asked to mark whether the statement is 'true' or 'false'. Items correctly answered are given a score of 1, and items answered incorrectly are given a score of 0. In the first section, item number 3 about the breast cancer prevalence was adjusted with the actual Indonesian prevalence rate. The total score ranged from 0 to 20, with higher scores indicating higher breast cancer knowledge. The BCKT has an acceptable reliability coefficient ( $\alpha = 0.69$ ).

### Illness perceptions

Patient's cognitive and emotional representation of illness was assessed using the BIPQ [27]. This instrument was constructed on the basis of the Common Sense Model of Illness Cognition, which assumes that illness perceptions will have an effect on patients' coping behaviors and psychological outcomes [28]. Illness perceptions consists of eight dimensions: (1) *consequences*, which reflect the expected effects and outcome of the illness; (2) *time line*, which refers to the perceived duration of the illness; (3) *personal control*, which reflects the beliefs about personal abilities to control the illness; (4) *treatment control*, which reflects the beliefs about the efficacy of the treatment to cure or manage the illness; (5) *identity*, which refers to the label the person uses to describe the illness and the symptoms; (6) *illness concern*, which refers to how much the person worries about his/her illness; (7) *coherence*, which refers to how well the person understands his/her illness; and (8) *emotional representation*, which reflects a person's evaluation of the potential emotional impact of the illness [27]. Each dimension is measured by a single item using a continuous linear 0–10 point scale. Answer scales of items about personal control, treatment control, and coherence were reversed to elicit the same response directions with the other five items. The overall score was obtained by summing the eight item scores where a

higher score indicates a more threatening view of the illness. Cronbach's alpha coefficient of the BIPQ is 0.70.

### Internal health locus of control

The internal health locus of control (HLC) was assessed using the internal HLC subscale of the MHLC Scales [29]. The MHLC was developed as a generic medical condition-specific measurement of locus of control that assesses individuals' feelings of control over their illness or disease, including the internal, chance, doctors, and powerful others subscales. This measure is an 18-item scale using a 6-point Likert format, ranging from 1 = 'strongly disagree' to 6 = 'strongly agree'. A higher score on each subscale is indicative of a stronger influence of the dimension in health behaviors. Cronbach's alpha coefficients of the MHLC scales ranged from 0.48 to 0.77.

### Satisfaction with cancer information

Patient satisfaction with the information provided was assessed using the SCIP [30]. This measure comprises two subscales: subscale 1 consists of 14 items that measure patient satisfaction with the amount and content of information. Patients are asked to rate each item using the following response scale: 'too much', 'about right', 'too little', and 'none wanted'. Patients who rate the items with either 'about right' or 'none wanted' are given a score of 1, whereas patients who rate the items with either 'too much' or 'too little' are given a score of 0. A subscale total score is obtained by summing the score for each item, which ranged from 0 to 14. High scores indicating a high degree of satisfaction with the amount and content of information received. Subscale 2 consists of seven items that measure patient satisfaction with the type and timing of information received. Patients are asked to rate each item on a five-response scale ranged from 'very satisfied' = 5 to 'very dissatisfied' = 0. The total subscale score ranged from 7 to 35, with higher scores indicating higher levels of satisfaction with the form and timing of information. The reliability coefficient for the Indonesian version of the SCIP was good (subscale 1  $\alpha = 0.77$  and subscale 2  $\alpha = 0.81$ ).

### Psychological distress

Psychological distress was assessed using the DT [31]. The DT was developed by the NCCN and is a one-item self-report measure of psychological distress in patients with cancer. Patients are asked to report their distress in the past week on a thermometer-like 11-point visual analog scale, with scores ranging from 0 (no distress) to 10 (extreme distress).

### Data analysis

All data analyses were performed using the IBM® SPSS® Statistics version 20. Descriptive statistics were used to



describe the demographic and clinical information, the mean scores of the questionnaires (i.e., the BCKT, the BIPQ, the MHLC, the SCIP, and the DT), and the non-adherence status. To explore the association between non-adherence and the demographic, clinical, and psychological variables, chi-square analyses were conducted for categorical variables, and *t*-test analyses were conducted for continuous variables. Backward stepwise logistic regression analyses were performed to analyze the association between psychosocial variables and non-adherence. The BCKT, the BIPQ, the Internal HLC, the SCIP, and the DT scores were the predictors, whereas treatment delay and not attending treatment appointment were the outcomes. In addition, backward stepwise logistic regression analyses were performed to explore the association between demographic and clinical characteristics and non-adherence. Age, marital status, education level, employment status, family incomes, travel time to hospital, and consult a traditional healer before and after diagnosis were the predictors, whereas treatment delay and not attending treatment appointment were the outcomes. For the logistic regression of not attending treatment appointments, current stage of cancer was also included as a predictor. A power calculation for 70 cases with six predictors in a linear regression analysis showed that a medium effect ( $f^2=0.21$ ) should exist in the population in order to find a significant effect ( $p=0.05$ ) [32].

## Results

### Demographic and clinical characteristics

The mean age of participants was 45.6 years ( $SD=7.88$ , range=28–66). Fifty-seven (81%) participants were married, and 46 (66%) participants were unemployed/housewives. The majority of participants had a lower education level (junior high school=16% and elementary school=51%). Fifty-three (76%) participants had a low monthly income (<\$200), and 28 (40%) had a travel time from home to the hospital >3 hours. Almost half of participants had an advanced stage of cancer (stage III=23% and stage IV=20). Demographic and clinical variables are summarized in Table 1.

### Non-adherence to treatment

#### Treatment delay

Seventeen (24%) out of 70 patients had delayed initiating treatment at HSH with a time delay ranging from 3 to 27 months, except for the two participants who had delayed treatment for 4 years. The median time of treatment delay was 7 months. In regard to demographic and clinical characteristics, we found that the stage of cancer and consulting a traditional healer before diagnosis were associated with treatment delay. Patients who delayed

**Table 1.** Demographic and clinical characteristics of study participants

Variable	n (%)
Age ( $M \pm SD$ )	45.60 $\pm$ 7.88
Marital status	
Married	57 (81%)
Single	2 (3%)
Widowed	11 (16%)
Education (highest)	
None	7 (10%)
Elementary school	36 (51%)
Junior high school	11 (16%)
Senior high school	10 (14%)
College or university	6 (9%)
Employment	
Housewife/unemployed	46 (66%)
Laborer/irregular job	18 (26%)
Private employee	1 (2%)
Government officer	5 (7%)
Family income (monthly)	
<\$200	53 (76%)
\$200–\$300	13 (18%)
>\$300	4 (6%)
Travel time to hospital	
<1 h	22 (31%)
2–3 h	20 (29%)
>3 h	28 (40%)
Months since diagnosis ( $M \pm SD$ )	22.6 $\pm$ 19.7
Range (months)	1–84
Current stage of cancer	
I	3 (4%)
2	37 (53%)
3	16 (23%)
4	14 (20%)
Treatment modality	
Mastectomy	32 (46%)
Chemotherapy	51 (73%)
Radiotherapy	12 (17%)
Health insurance	
Yes	66 (94%)
No	4 (6%)
Family history of breast cancer	
Yes	14 (20%)
No	56 (80%)
Consult a traditional healer	
Before diagnosis	33 (47%)
After diagnosis	12 (17%)

initiating treatment were more likely to be at an advanced cancer stage (stage III and IV) ( $\chi^2=9.244$ ,  $df=3$ ,  $p=0.03$ ) and had more frequently consulted a traditional healer before their diagnoses ( $\chi^2=4.953$ ,  $df=1$ ,  $p=0.03$ ). Means, standard deviations, and range of the psychological variable scores are detailed in Table 2. The *t*-test results showed no significant differences on any of the psychological variables between patients who delayed initiating treatment and who did not. Backward stepwise logistic regression analyses found that consulting a traditional healer before diagnosis was the only significant predictor of treatment delay ( $\beta=1.27$ ,  $p=0.04$ ).

**Table 2.** Means, standard deviations, and *t*-test results of the psychological variables of the non-adherers and the adherers group

Measure	Initiating a recommended treatment				Attending appointments			
	Adherers		Non-adherers		Adherers		Non-adherers	
	(n = 53)		(n = 17)		n = 61		n = 9	
	Mean (SD)	Mean (SD)	t-test	p-value	Mean (SD)	Mean (SD)	t-test	p-value
Distress	4.58 (2.76)	4.82 (2.60)	−0.315	0.75	4.46 (2.66)	5.89 (2.80)	−1.495	0.14
Internal health locus of control	24.57 (4.18)	23.59 (4.53)	0.823	0.41	23.97 (4.08)	26.78 (4.84)	−1.885	0.06
Satisfaction with the amount and content of information	5.40 (3.50)	4.76 (2.75)	0.679	0.50	5.34 (3.28)	4.56 (3.75)	0.662	0.51
Satisfaction with the form and timing of information	23.23 (4.07)	21.47 (4.11)	1.544	0.13	<b>23.21 (3.89)</b>	<b>20 (4.72)</b>	<b>2.247</b>	<b>0.03</b>
Illness perception	38.51 (9.35)	39.94 (13.25)	−0.414	0.68	<b>37.70 (10.26)</b>	<b>46.67 (7.35)</b>	<b>−2.520</b>	<b>0.01</b>
Breast cancer knowledge	9.42 (4.16)	8.82 (4.16)	0.582	0.56	9.18 (3.63)	9.89 (3.79)	−0.544	0.59

SD, standard deviation.

### Not attending treatment appointments

Nine (13%) out of 70 patients reported that they had missed two or more consecutive treatment sessions. In regard to demographic and clinical characteristics, we found that only consulting a traditional healer after diagnosis was associated with missing two or more consecutive treatment sessions ( $\chi^2 = 5.420$ ,  $df = 1$ ,  $p = 0.02$ ). Means, standard deviations, and range of the psychological variable scores are detailed in Table 2. The *t*-test results showed that patients who had missed two or more consecutive sessions had lower satisfaction with the type and timing of information provided ( $t = 2.247$ ,  $p = 0.03$ ) and more negative illness perceptions (i.e., a more threatening view of cancer) ( $t = -2.520$ ,  $p = 0.01$ ) than patients who had not missed two or more consecutive sessions. Backward stepwise logistic regression analyses found that illness perception ( $\beta = 0.10$ ,  $p = 0.02$ ) was the only significant psychological predictor of missing two or more consecutive treatment sessions. Post hoc logistic regression analysis showed that only treatment control dimension significantly predicted missing treatment sessions ( $\beta = 0.39$ ,  $p = 0.03$ ). In addition, consulting a traditional healer after diagnosis ( $\beta = 1.67$ ,  $p = 0.03$ ) was a significant demographic predictor of missing two or more consecutive treatment sessions.

### Discussion

The present study showed that 24% of breast cancer patients reported that they had delayed initiating treatment at the hospital and 13% of breast cancer patients had missed two or more consecutive treatment sessions. In the bivariate analyses, we found that patients who had missed two or more consecutive sessions had lower satisfaction with the type and timing of information provided and more negative illness perceptions than patients who had not. In multivariate regression analyses, consulting a traditional healer before diagnosis was associated with treatment delay. Having more negative illness perceptions and consulting a traditional healer after diagnosis were

associated with missing two or more consecutive treatment sessions. Contrary to our expectations, patients' level of knowledge, internal HLC, and distress were associated with neither treatment delay nor missing treatment sessions.

Of the 70 patients who were currently receiving treatment for their breast cancer, 24% reported that they delayed initiating treatment after their diagnosis, which is lower than our previous study that found 40% delayed initiating treatment [11]. One possible explanation for this difference may be related to the clinical characteristics of the patients. We found that the majority of patients (57%) in the current study were at stage I and II and therefore probably had more positive expectations; whereas in the previous study, the majority of patients (64%) were at stage III and IV. Nevertheless, this finding was higher than a recent study in South-East Asian breast cancer patients that found 7% of patients delayed initiating treatment at the hospital [33]. Thirteen percent of patients were non-adherent to treatment by missing two or more consecutive treatment sessions. The current non-adherence rate was lower than a previous study among Nigerian breast cancer patients, which used a similar definition of non-adherence as the current study. Approximately 80% of patients missed two consecutive doses of chemotherapy. Financial problems, fear of operation, and a strong belief in traditional healers were the most frequent reasons for non-adherence to treatment [25].

Having more negative illness perceptions was associated with missing treatment sessions. These results are in concordance with the result of a recent review study that found a negative association between illness perception and adherence to medication [18]. According to the Common Sense Model of Illness, patients create cognitive and emotional representations of the illness as responses to symptoms and signs of illness, and those perceptions will lead to their coping responses [27]. In this study, we found that a low belief in treatment efficacy is associated with missing treatment sessions, which is similar to previous studies findings among diabetes and hypertension patients that found patients who felt treatment could control their illness were more likely to take their medication as prescribed [34,35].

In bivariate analyses, lower satisfaction with information provided was found to be associated with missing treatment sessions. This finding is in line with previous literature, which found that greater satisfaction with information was associated with higher adherence to medical recommendations and treatments [36,37]. However, this association was not significant in multivariate analyses. One possible explanation for this result is a high collinearity between illness perception and satisfaction with information ( $r = -0.35$ ,  $p < 0.01$ ); therefore, multivariate analyses showed only the strongest predictor (i.e., illness perceptions) of missing treatment sessions.

We found that consulting a traditional healer before diagnosis was a risk factor for treatment delay and consulting a traditional healer after diagnosis was a risk factor for missing treatment sessions. This finding supports the results of our previous study that identified a strong belief in traditional healers as one of the main barriers of non-adherence to treatment [11].

Several methodological limitations should be noted. First, this study is based on consecutive patients where the majority has low socio-economic status because HSH is a referral hospital for the poor people. The relatively small sample size and homogeneity of the current sample could have some influence on the results. For example, a review study of 50 years of research about adherence to medical recommendations found that studies with smaller sample sizes reported higher adherence than larger samples [7]. Therefore, the adherence rate obtained in this study should be interpreted with caution and may not represent the general Indonesian cancer patient population. Second, non-adherence was measured through patients' self report in a retrospective way. Therefore, patients' responses were vulnerable to recall and social desirability bias, which may

have resulted in an underestimation of non-adherence. Lastly, the cross-sectional design of the study limits the causal association between psychological factors and non-adherence to treatment. Moreover, the psychological variables were measured after the occurrence of non-adherence, and patients' knowledge and distress at the time of measurement may not have been the same as at the time of non-adherence. Thus, further prospective studies are needed to ascertain the current study findings.

Our study sheds light on the importance of illness perceptions and the belief in traditional healers in explaining non-adherence to treatment. The relative importance of these factors should be studied in future prospective studies. Our results suggest that health professionals need to be aware of patients' threatening view of cancer and its medical treatment, and their unrealistic belief in traditional healers. If they provide patients with clear information about their illness and its treatment, patients' misunderstanding and negative conceptualization of the illness might be eliminated, which in turn may lead to better adherence to medical treatment [38].

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## Conflict of interest

The authors have declared no conflicts of interest.

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